Title: Patient and companion concerns when receiving a dementia diagnosis: An observational study of doctor-patient consultations.

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Abstract

Objective: To examine patient/companion concerns expressed during dementia diagnostic feedback meetings and how doctors respond to these concerns.
Methods: 60 video-recorded consultations between psychiatrists/geriatricians and patients/companions. Patient/companion concerns and doctor responses were coded, content analysed and grouped into categories.
Results: An average of 4 concerns per consultation were expressed. Forgetting words, people and events; emotional reaction to the diagnosis and frustration about symptoms were the most common patient concerns. Companions expressed concerns about the patient's physical health, problems caused by forgetting, and stigma of dementia. Doctors actively invite patients/companions to express concerns and respond to these. Concerns elicited by the doctor were more likely to be elaborated upon than concerns that were volunteered. Doctors encouraged elaboration of most concerns, however they discouraged elaboration of over a third of concerns, and the majority of 'prognosis' and 'physical health' concerns.
Conclusion: Patients express frustration at how the symptoms of dementia manifest in their daily life along with confusion and shock at the diagnosis.
Practice Implications: Whilst most concerns led to further discussion, 38% were given a response that discouraged elaboration, including prognosis. Doctors can attend to concerns by not changing topic, use exploratory questions and engage with the specific type of concern.

Keywords: dementia, concern, communication, medical consultation

1. Introduction

Estimates show that 46.8 million people worldwide were living with dementia in 2015 and the number is steadily increasing [1]. Receiving a diagnosis of dementia is a life-changing event, raising significant concerns and considerable distress to patients and their companions. Improving doctor-patient communication at the dementia diagnostic feedback meeting can have a significant positive impact.

An important aspect of doctor-patient communication is the way doctors elicit and respond to concerns expressed by patients, where concerns are defined as patient expressions that convey worries, fears, or unpleasant emotions [2]. Although eliciting patient concerns might prolong the diagnostic appointment [3], encouraging their expression can lead to improved outcomes, such as doctors being able to detect psychiatric conditions and improve engagement of patients in health services who might otherwise not engage [2, 4]. Research on cancer consultations has shown that not addressing patient concerns can have a negative impact patient's subsequent psychological well being [5]. Despite these benefits, a review of the literature shows that physicians do not always detect patient concerns and may discourage their disclosure [2], which may reflect issues in the power dynamics in discourse occurring in doctor-patient communication [6].

Dementia consultations usually involve the person with dementia, their carer and the doctor, which can create additional communication imbalances [7-8], as the wishes/concerns of both the patient and carer need to be considered. However evidence suggests that patients are often excluded in these triadic consultations [9]. Equally, there is the impact of dementia symptoms on communication that needs to be considered, as dementia involves language decline and comprehension problems [10].

Various frameworks and instruments have been developed that explore patients' emotional expressions during doctor-patient communication [11-12], such as the Roter Interaction Analysis System (RIAS) [13,14] and the Verona Coding Scheme for Emotional Sequences (VR-CoDES) [15]. These explore emotional sequences expressed by patients and professional responses to concerns [15-17], focusing not only the importance of identifying patient concerns but also whether doctors provide space for patients to elaborate on their concerns and whether patients receive an empathetic response [2,16-17].

In this study we explored concerns expressed **in** doctor-patient-companion communication in specialist memory clinics during the dementia diagnostic feedback meeting. The aim was to identify concerns expressed by patients and companions, whether doctors elicit patient/companion concerns and how they respond to these concerns.

2. Methods

2.1 Setting and participants

This study was part of a cohort observation study: Shared Decision Making in Mild to Moderate Dementia (ShareD: 13/114/93). Data was collected in the form of video recordings from 9 specialist memory clinics over 4 NHS trusts (1 in Devon and 3 in London), from May 2014 to February 2016. The first 60 consultations were selected from the larger sample for analysis.

Patients were referred to the memory clinic by their GP and were asked to attend the appointment with a family member or someone who knows them well. The appointment consisted of history taking, cognitive assessment, neuroimaging and diagnostic feedback. In London, assessment and diagnosis occurred over a period of months whereas in Devon they took place on the same day.

19 doctors, 60 patients (37 women, 23 men) and 59 companions were observed. 35 patients were from London and 25 from Devon. Patients were aged from 52 to 92 years with an average age of 81 years. In 90% of the consultations there was one companion present and in 8% there were two companions present. Doctors were either psychiatrists or geriatricians who delivered the diagnosis to the patient/companion. The doctors consent rate was 88%. 13 doctors had more than 1 patient/consultation observed, ranging from 1 (4 doctors) to 6 (1 doctor). In 12 appointments other healthcare professionals, such as dementia advisors (service providing information and signposting), nurses and medical students, attended the meeting and participated in discussions.

2.2. Recruitment and Ethics

Doctors working in memory clinics were identified in the participating trusts, and contacted first by email and then by telephone. Patients who had been referred by their general practitioner and were due to attend an appointment with the participating doctors' memory clinic were eligible and were identified by administrative staff before their appointment, by review of medical records. Inclusion criteria were mild to moderate dementia and capacity to consent. Patients who required interpreters were excluded from the study. When the patient and their companion arrived at the clinic, a researcher approached them to discuss the study and obtain written, informed consent. For patients without capacity (one patient in our sample) we followed the "Guidance on nominating a consultee for research involving adults who lack capacity to consent" [18]. This study was approved by the NRES Committee London, North East REC Office (REC reference: 13/LO/1309).

2.3. Design and data analysis

The diagnostic feedback meetings were videotaped using GoPro HERO3 cameras, and audio recorded to ensure maximum chance of quality audio capture. The researcher was not present to minimise observer effects. Recordings were transcribed verbatim by professional transcribers, including additional features such as pauses, laughter and acknowledgment tokens (e.g. hm). The video recordings (from 2 cameras) were used during coding to identify patients, carers and doctors' facial and emotional expressions and when it was not clear from the transcript if the doctor was speaking to the patient or the carer.

The diagnostic feedback consultations of 60 patients were coded. Patient/companion concerns were either *volunteered* or *elicited* by the doctor i.e. when the doctor solicited or facilitated the expression of a concern [15]. This included for example prompting the patient or their companion to talk about their reaction to the diagnosis *"what do you think about the diagnosis";* and eliciting concerns regarding the stigma of dementia *"all of that can for some people can be something that they don't want to hear, how do you feel about that? ".*

Patient and companion concerns (elicited or volunteered) and doctors' responses, were coded using a 'concern and response coding framework' (figure 1). The frequency of concerns and responses were identified. All patient concerns, companion concerns and doctor elicitations were content analysed [19] and organised into categories. Concerns were identified inductively from the transcripts [20], and defined as issues topicalised by the patient or their companion that were not dementia specific symptoms, including: patients' physical health problems; psychological

aspects (worried, anxious, afraid, upset, frustrated, embarrassed); negative consequences of symptoms of dementia (i.e. irritating people, getting confused, feel like an idiot); associated dependency arising from symptoms; stigma and response to diagnosis (shocked, not prepared).

Responses and elicitations from all healthcare professionals present were coded and 80% were attributable to the doctor. We coded doctor's initial response according to the Verona coding scheme [15]. The initial response of the doctor to the concern was coded as either encouraging or discouraging elaboration of the concern (Fig. 1). Encouraging elaboration was characterised by: pauses inviting the patient to continue; acknowledgment or agreement tokens (yes, hmm, okay); or a more substantive verbal response, e.g. one that aimed to advise or reassure. Responses discouraging elaboration were not providing space for the patient/companion to further elaborate on their concern by providing a minimal response and/or an immediate change of topic.

Reliability
The coding was developed inductively in 4 analytic meetings between RM, PX and IM. A further 5 meetings took place at the analytic stage to discuss cases that were uncertain, for example when it was unclear whether there was an expression of concern, for example when patients were explaining symptoms: *Patient: "(memory) ain't like it was but it's not terrible"*; and cases where utterances across a number of turns related to the same concern. 28 cases that were not clear were discussed to resolve disagreement.

Inter-rater reliability: Transcripts were coded by one author (IM) and a second rater (PX) coded 15% (randomly selected) of the total 60 transcripts in order to establish interrater reliability. Cohen's Kappa [21] was calculated using Stata [22]. The second coder identified 5 new patient-volunteered concerns not identified by the first coder. Overall agreement was 89% (mean of the agreement of individual weighted kappas). For patient concern kappa = 0.73; carer concern kappa = 1; response encouraging elaboration (patient) kappa = 0.83; response discouraging elaboration (patient) kappa = 0.83; response discouraging elaboration (carer) kappa = 1; response encouraging elaboration (carer) kappa = 1.

3. Results

In 54 of the 60 consultations at least one patient concern was coded, and in 36 of the 60 consultations at least one companion concern was coded. In 5 consultations there were no patient or carer concerns raised, however there were doctor invitations to elicit concerns in all these consultations.

An average of 4 patient/companion concerns per consultation were identified. A total of 249 concerns were identified, including both patient/companion volunteered and doctor elicited. Figure 1 below presents the total frequencies elicited/invited versus volunteered concerns and response type (encourage/discourage elaboration).

Figure 1 here

3.1 Doctors elicitations

There were a total of 181 doctor invitations, across 59 consultations, to elicit patient/companion concerns, 3 elicitations on average per consultation (Fig. 1). In the one consultation were there was no elicitation of concerns by the doctor, 1 patient and 5 carer concerns were expressed.

70 invitations to elicit concern were not followed up by a patient/companion concern. Elicitations of patient concerns involved for example the disclosure of diagnosis, e.g., *"are you someone that would want to know that or do you think you'd find that a bit depressing?"* and the stigma of dementia, e.g., *"it's a scary word for people to hear because we associate it with things"*. In Devon, doctors elicited concerns relating to tests, scans and diagnostic feedback all taking place in one day, e.g., "*it's a lot to take on board today, you know because, you're going from just coming in to have a memory test to, having a prescription for something for Alzheimer's disease".*

Some elicitations were addressed to the companion, for example, eliciting concerns about being a carer, e.g., *"I guess that you're the one Mr (name) who actually has to bear the brunt of all of this and all these changes"*; and managing on a daily basis e.g., "*do you have any worries about do you know managing from day to day"*.

There were 4 instances where the companion elicited a patient's concern, for example their reaction to the diagnosis: c*ompanion* e.g., *"does it bother you… that the doctor's telling you have dementia I mean, does it frighten you?"*.

3.2 Patient concerns

Table 1 presents the concerns expressed by patients. The most common concerns were in relation to *'emotional reaction to diagnosis'* (31 occurrences) which involved personal experiences of knowing other people with dementia and negative representations of dementia e.g., "*I have a picture of myself going bonkers* ***(P19)"***; responses to the word dementia e.g., *"I don't want to hear that word it's scary* ***(P21)*****"**; and concerns raised as a result of the disclosure of diagnosis e.g., *"I didn't think you were going to tell me this* ***(P19)".***

Other issues that concerned patients involved *'Forgetting words, people and events'* (26 occurrences). This involved worries about remembering names and things that happened recently, difficulties recognising familiar people and places e.g., *"say I watch Coronation Street you say what was is about half an hour after, I can't even tell you* ***(P33)";*** and expressed frustration (25 occurrences) about losing competencies e.g., "*they exasperate me and frustrate me, looking for a word* ***(P24)****",* and worry about the impact of their memory problems e.g., *"when something happens or anything, I'm I sort of afterwards think oh I've lost my cool*" **(P79).**

Concerns were also expressed in relation to specific patient circumstances and past traumatic events, e.g., *"sometimes I feel really awful about what happened, when I think about it* ***(P35)****";* about prognosis e.g., "*what does the future hold for me* ***(P117)***" and progression of dementia symptoms e.g., *"will it gradually get worse?* ***(P42)".***

As one of the objectives of the diagnostic meeting was to discuss treatment where appropriate, a number of concerns related to medication, including concerns about new tablets, side effects and how to manage treatment, **e.g.,** *"I live on my own so I don't want any drastic treatment* ***(P57)****".* Other concerns expressed by patients involved physical problems: "*it's no fun when you're in pain all the time* ***(P21)****",* and they raised concerns about events in their lives (e.g., loss of a family member), socialising/being alone, and feelings about being cared for e.g., "*I hate being nursed* ***(P82)*****".**

Category	Definition	Frequency	Example
Emotional reaction to diagnosis	Reaction to the diagnosis (shocked, depressed, confused), personal experience of dementia and stigma of dementia	31	"what's worrying me, all I keep seeing on the telly is people and they got, I can't even say the word because that upsets me" **(P21)**
Forgetting words, people and events	Difficulty remembering things, such as dates, name, financial details, places and worries about losing competence, e.g. spelling a word	26	"I'm often asking you know, what's the word for" **(P19)**
Frustration about memory problems	Awareness and negative impact of symptoms of dementia (irritated, embarrassed, confused, feel like an idiot)	25	"I feel also it must be very irritating for other people **(P19)".**
Worries about family/death of close people	Loss of family and friends and concerns about leaving family and children alone after death	17	"sometimes I get really upset and worried, 'cause I got the photo thing and every time I look at it, I just feel really really awful" **(P35)**
Prognosis	Worries about the future, getting progressively worse or becoming violent	12	"because of late I have experienced a real deterioration and a steady worsening of my memory" **(P24)**
Physical health	Physical complaints sleeplessness, tiredness and giddiness	12	"I don't know, I feel extremely tired, I can walk very short distance and then I have to sit down" **(P24)**
Stress/Psychological symptoms	Stress, hallucinations, compulsive behaviour, depression	11	"but you see I am a stressful person, I'll just I get stressed" **(P82)**

Medication	Worries about side effects, how to manage taking tablets	10	"you make me worried really because I am on my own" **(P57)**
Other	Issues from the past, difficult life events	8	"I didn't go through a good life, in my way, when I was home, when my mother died" **(P33)**
Not going out/seeing people	Reduced opportunities to go out e.g. spouse cannot drive, worries about going out alone, not having people around/being alone	7	"would like to get out of the house now and then" **(P36)**
Being cared for	Being dependant on others	5	"but you see I hate being fussed over" **(P28)**

Table 1. Patients' concerns domains.

3.3 Companion concerns

Table 2 presents the concerns expressed by companions. The most common (17 occurrences) was 'Personal experience/stigma of dementia', which included concerns relating to previous experiences of dementia e.g., "*I had a friend that- they had a dementia and they ended up being very violent **(C23)"*.** Other common concerns expressed by companions related to patient's physical health (16 occurrences), which involved worries about the patient's health in general e.g., *"we thought he had a balance problem, quite concerned about it actually **(C83)**"*. Overall, concerns expressed by the companions were similar to those expressed by the patients, for example traumatic events (e.g. family death, 14 occurrences); Patient's emotional state (14 occurrences) e.g., *"sometimes she does have these, fearful attacks **(C35)"*; and** worries about the patient memory problems (12 occurrences) e.g., *"mum has at times been confused about dates **(C84)**"*.

Other concerns involved the patient not accepting they have memory problems e.g., *"I think (patient name) doesn't want to admit that there is a problem as such **(C27)**"*. Also making plans for the future, such as caring arrangements concerned some companions e.g., *"I do feel a bit in inhibited on sort of going ahead, with making plans for a long term carer **(C83)"*.**

Category	**Definition**	**Frequency**	**Example**
Personal experience/stigma of dementia	Understanding what dementia means, for example knowing someone else with dementia and response to diagnosis	17	"I've seen people with it, I've been helping my neighbour two or three doors down and I've seen his, I was worried it was going to turn out like that" **(C126)**
Physical health	Other patient physical complaints: balance, visual problems and sleeplessness.	16	"I am a little bit worried, in case there's a valve not working or something's blocked" **(C66)**
Worries about family/death of close people	Loss of family/friends and traumatic impact on the patient	14	"we had a terrible well tragedy in the family, her brother" **(C35)**
Patient's emotional state	Worries about patient's state of mind (nervous, confused, stressed, anxious)	13	"I go round and she goes, oh I wish I was dead" **(C06)**
Patient forgetting/ confused/not accepting memory problems	Worries about patient's memory problems: forgetting things, repeating conversations, difficulty understanding conversations and not admitting problems	12	"I find the hardest thing is she won't accept that she's got memory (problems)" (**C62)**
Patient's ability to manage day to day living	How patient can manage life day to day, such as bank cards, money and financial affairs	3	"how mum may be when she feels confused, how she can manage" **(C10)**
Being a carer	Carer role and burden	4	"sometimes how can I say I don't get annoyed really but I think say I've just told you you know and you talk like that" **(C23)**

Patient's ability to manage medication	How patient can manage taking tablets from day to day	6	"they must have picked up on the medication and giving mum a blister pack, for each day of the week, and the pills are already sorted so she doesn't have to juggle lots of different packets" **(C102)**

Table 2. Companions' concerns domains.

3.4 Doctor response to concerns

All 249 concerns were given a response by the doctors. The majority of these (62%) were given a response that encouraged elaboration. However, in more than a third (38%) of patient/carer concerns, elaboration was discouraged by doctors.

When concerns were elicited by doctors, they were more likely to respond by encouraging elaboration of the concern (71%) than not (29%). On the other hand, when concerns were volunteered by the patient/companion, doctors were (comparatively) more likely to discourage elaboration of the concern (55%) than not (45%) (Figure 1).

Looking at the different areas of concern (table 3), doctors encouraged more elaboration of concerns about 'emotional impact of memory problems', 'worries about family', 'being cared for/being a carer' and 'stress/psychological symptoms'. In contrast, doctors discouraged elaboration of the majority of concerns relating to 'prognosis' and 'physical health'. Other concerns that were not elaborated upon included more than one third of 'forgetting words, people and events', 'emotional response to diagnosis' concerns and 'medication' concerns and almost a third of 'emotional impact of memory problems'.

Concerns	**Response Type**		**Total**
	Encouraged elaboration	Discouraged elaboration	
Emotional response to diagnosis	29 **(59.2%)**	20 **(40.8%)**	49
Forgetting words, people and events	22 **(57.9%)**	16 **(42.1%)**	38
Emotional impact of memory problems	27 **(73%)**	10 **(27%)**	37
Worries about family/death of close people	25 **(80.6%)**	6 **(10.4%)**	31
Patient physical health	13 **(46.4%)**	15 **(53.6%)**	28
Other	7 **(50%)**	7 **(50%)**	14
Prognosis	3 **(23%)**	10 **(77%)**	13
Medication	8 **(66.7%)**	4 **(33.3%)**	12
Stress/Psychological symptoms	9 **(82.9%)**	2 **(17.1%)**	11
Being cared for/being a carer	8 **(88.9%)**	1 **(11.1%)**	9
Patient not going out/seeing people	4 **(57.1%)**	3 **(42.9%)**	7
Total	*155* ***(62.2%)***	*94* ***(37.8%)***	*249*

Table 3. Doctor response type and concern (patient/companion merged).

3.4.1 Encouraging elaboration of concerns

In 62% of their responses, doctors provided responses to patient concerns that facilitated further discussion and involved giving space for the patient or companion to further express their concern. For example below, the doctor provides an acknowledgement that they're listening ("yeah") and then pauses, allowing for the companion to continue expressing their concern:

Companion: I think (patient name) doesn't want to admit that, there is a problem as such you know you
Doctor: yeah (pause)

Doctors also addressed the concerns expressed by the patients, by offering a normalising response ("some people"):

Patient: I'm hoping it's not a grave thing
Doctor: I don't think it is a grave thing

Patient: hmm
Doctor: Some people don't like hearing it because it can be a scary thing sometimes, but I think what I'm saying today is that you've been having these little problems over time and now what we've been able to do is we've got a name for it

Finally, doctors provided comprehensive and often empathetic responses aimed to advise and reassure, and by providing practical solutions:

Patient: I don't want to be a burden to my children
Doctor: no I mean, I think it seems that they are, they're doing, little bits and bobs for you
Patient: yeah that's it
Doctor: as I said before if it ever gets to be a problem, there's other support and other help
Patient: okay
Doctor: so, I wouldn't feel like, I wouldn't worry too much about that at this stage

In the example below the doctor encourages elaboration of the concern by, allowing for the patient to pause and complete the expression of the concern, confirming that they are actively listening ('yes'), and then responding by aiming to reassure the patient about their diagnosis.

Patient: is this a serious problem for me at the moment, I would not think that my memory was so bad that I would forget lots and lots of things, it's usually (pause)
Doctor: yes
Patient: small things, you know rather than, (pause)
Doctor: I think you're right and, what, you know we would call this a, you know it's certainly at the mild or early end of the spectrum of memory problems

3.4.2 Discouraging elaboration of concerns

In almost half of the concerns that were volunteered by patients/companions, doctors discouraged elaboration by moving onto a different topic. In a few cases the doctors provided a passing/brief response and changed the topic immediately:

Patient: I wasn't very keen on the, hospital
Doctor: you weren't, well that's quite normal, we are going to worry when people are keen to be in hospital. Right, now, the other thing that - he said was that you'd, that you were on tramadol for pain

In other instances the doctor provided a minimal continuer passing the opportunity to respond more substantively ("hmm") and then changed the topic:

Patient: I got fits, 9 years of age
Doctor: hmm
Patient: you know what I mean, I grew up, if I see my mother and father I would go into a fit and stuff like that
Doctor: okay, alright, so I think that the most important thing you can do to help your memory really is to stay off the alcohol

Finally, there were cases when the doctor did not provide any acknowledgement or response and moved on to a different topic, in this case checking the patient's pulse:

Patient: it's awful when you're forgetting things
Doctor: alright let me just check your pulse

4. Discussion and Conclusion

4.1 Discussion

The majority of dementia diagnostic feedback consultations had at least 1 patient/companion concern with 4 concerns on average expressed per consultation. Patient and companion concerns related to patient's memory problems, reaction to receiving the diagnosis, stigma about the diagnosis, the patient's emotional state, medication and prognosis. In line with other research [e.g. 23-25], we found that patients with dementia and their companions express distress and shock on hearing the diagnosis itself.

In contrast to research in cancer consultations where doctors do not explicitly invite patients to express concerns [26], and a review that found that physicians often discourage the disclosure of concerns [2], we found that 45% of patient/companion concerns were elicited by the doctor. In line with calls for more patient-centred care in dementia [23], we found that this sample of doctors elicited concerns, predominantly about the patient's psychological state, by directly asking the patients with dementia how they felt. Although there were 5 consultations were no concerns were expressed, this was not due to lack of opportunity as doctors invited the expression of concerns. Doctors eliciting patient concerns could be particularly beneficial for this population as people with dementia show reduced conversational initiation [10].

However, although doctors elicited patient/companion concerns and responded by encouraging elaboration of most concerns (62%), elaboration on a significant number of concerns raised (38%) was discouraged. When concerns where elicited by the doctor, doctors generally provided more space to discuss concerns, however this was not the case when concerns were volunteered by the patient/companion, and in some cases there was a change of topic [27]. Doctors discouraged discussion of most prognosis concerns. This is also found in cancer literature where in some cases and during the initial consultation, there is not an explicit discussion about prognosis [28]. This might lead to reduced opportunities for patients and their families to adjust their lives accordingly and aim towards attainable goals [29-30]. Doctors also discouraged discussion of most 'physical health' concerns. This could be because they consider these kinds of medical problems to be outside the remit of the dementia diagnostic feedback consultation. Concerns about the side effects of anti-dementia medication and patient's ability to manage medication, were expressed by both patients and companions and doctors discouraged elaboration of a third of these concerns. As medication is routinely discussed in these diagnostic meetings, when appropriate, addressing medication concerns is important in increasing patient involvement in decision-making [31].

The discouragement of elaboration of a significant number of concerns might suggest a difficulty on the part of doctors in responding attentively to patient concerns and the power dynamics in doctor-patient communication. Heritage [6], for example, describes how the topical agenda of doctor-patient consultations is driven by the doctor by virtue of their role as questioner. In institutional encounters, the person asking questions is in a position of power. Doctor-patient communication could be improved by doctors attending to patient/companion concerns, by not changing the topic, following up concerns with exploratory questions, and engaging with the specific type of concern (e.g. additional support from social services).

Finally, doctors addressed both the patient and the companion when they elicited and responded to concerns. This is important in triadic consultations as it was previously found that doctors shift from talking to the patient to talking to the carer about the patient [8]. It also supports research [32] that suggests that couples who receive a diagnosis of dementia should be helped to create a joint construction of their situation to manage with the impact of dementia. Additionally, in 4 cases, companions elicited patient concerns related to patient's reaction to the diagnosis. In this way, companions may be acting to include the patient's voice on delicate issues in the consultation.

Strengths: The analysis was based on real time video-recordings rather than interviews and included a range of doctors from multiple services across urban and rural areas.

Limitations: There were some positive emotions expressed in the consultations, however, the low frequency did not lend itself to systematic coding. Although discrete cameras were used, video recording the consultations could have had an impact on the doctor-patient interactions. There could also be selection bias for the doctors/patients who agreed to participate. The doctors who agreed to participate may have been more interested in communication while the patients may have been more engaged in the memory clinic process. We did not code 'within doctor' patterns as for 6 doctors we only have data for 1 consultation. Reliability coding was conducted on 15% of the sample and although there was high agreement across all categories, there was some variation across coders in identifying a patient concern.

4.2 Conclusion

Patients express frustration and annoyance at how the symptoms of dementia manifest in their day to day lives, confusion along with shock at the diagnosis and worry about negative portrayals of dementia. Companions express similar concerns including the patient's physical health. Doctors actively elicited and addressed concerns, however, more than two-thirds of concerns were not addressed. Findings suggest that there is reluctance to discuss the delicate issue of what the future holds and the progression of dementia over time. In addition, there was reluctance to further discussion about patients' physical health concerns, the emotional response to the diagnosis (patients' articulating shock, confusion, the stigma of dementia) and forgetting.

4.3 Practice implications

For doctors and other healthcare professionals involved in the dementia diagnostic process, it may be helpful to be aware of the types of concerns patients and companions express when receiving the diagnosis. This may help to proactively attend to these concerns and support long-term planning, thereby reducing anxiety for people. Future work should be conducted on the ethical issues involved in communicating a diagnosis of dementia, including prognosis and how much information is provided at the point of diagnosis. A more in-depth analysis such as conversation analysis could identify further concerns and allow a more sophisticated analysis of doctor responses to concerns.

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Informed consent and patient details
We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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